DOCUMENT RESUME

ED 322 922 IR 053 241

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TITLE The Responsibility of Librarians for Collecting and Making AIDS Materials Available.
PUB DATE 89
NOTE 18p.; Paper presented at the Annual Conference of the Utah Library Association (St. George, UT, February 15-17, 1989).
PUB TYPE Viewpoints (120) -- Reports - Evaluative/Feasibility (142)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Academic Libraries; *Acquired Immune Deficiency Syndrome; Health Education; *Health Materials; *Information Dissemination; Library Collection Development; *Library Role; *Public Libraries; Research Tools; *Social Attitudes; Social Problems; User Needs (Information)

ABSTRACT

This paper is a call for academic and public libraries to contemplate their role in meeting the Acquired Immune Deficiency Syndrome (AIDS) information needs of their patrons. Librarians are urged to consider the potential negative consequences of neglecting to provide up-to-date and representative collections of AIDS materials. It is suggested that optimum success in collecting and disseminating AIDS materials depends on the librarian's knowledge of the many facets of AIDS research and understanding the content of the medical, popular, and social science literature. Several bibliographic guides to articles and papers from the medical literature are recommended for providing access to patients on all aspects of the disease. Librarians are cautioned to exercise care when referring patrons to the popular press, which may contain inaccurate, redundant, or contradictory information, and to favor the most recent articles. A brief review of how AIDS has been perceived and portrayed by the popular press points out that, until 1984 when it obtained its own heading, AIDS was listed under "Homosexuality" in periodicals indexes. Libraries with strong social science collections, particularly in psychology, social work, medical sociology, and medical anthropology are encouraged to offer support to patrons undertaking social science research on AIDS, and two social science indexes are recommended as resources for psychosocial AIDS researchers. (57 references) (SD)

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THE RESPONSIBILITY OF LIBRARIANS FOR COLLECTING AND MAKING AIDS MATERIALS AVAILABLE

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Domestic and international concern with Acquired Immune Deficiency Syndrome (AIDS) with its devastating medical, psychological and social impact continues, like the disease, to spread. Certainly no health occurence in recent history has caused such global impact, medical consternation, or bureaucratic indecision. AIDS poses a challenge for those undertaking biomedical and social research, those providing health care and for numerous social institutions including public and academic libraries which have a responsibility for collecting and making available the voluminous documents dealing with AIDS. In the absence of a cure or vaccine, current hope lies in what the research of the biomedical and the social and behavorial sciences can devise to help slow or halt the epidemic's spread. Essential to this research process is ready access to published materials. It is in collecting and making available materials on AIDS that academic and public libraries can make an important contribution to the AIDS battle. Those affiliated with libraries lacking up to date and representative collections of AIDS materials should consider the potential negative consequences of such an oversight, and seriously consider the role libraries can play in meeting the AIDS information needs of their patrons. Optimum success in collecting and making AIDS materials available depends to a great extent on librarian's knowledge of the many facets of AIDS research and understanding

of the content of the medical, popular and social science literature.

AIDS IS RECOGNIZED

When the center for Disease Control (CDC) first described AIDS in 1981, no one could have guessed at the health and social implications of this devastating disease or of the quantity of published material that would be devoted to it. As one might expect in the case of a disease, the first published documents dealing with AIDS were of a medical nature. The CDC has the dubious honor of having published the first description of AIDS. This one page document appeared in the June 5, 1981 CDC's *Morbidity and Mortality Weekly Report*. Here it was reported that for unexplained reasons, unusual malignancies, opportunistic infections and immune system abnormalities were appearing in a number of previously healthy young homosexual men in Los Angeles, California. Alarmingly, other cases were reported the following month when twenty male homosexuals were similarly diagnosed in New York City.[1] These cases on both coasts of the United States shared a common factor, immune systems that had been weakened or destroyed. While no causative agent was immediately identified, it was suggested that patterns of sexual relations in gay communities might be responsible for the disease's spread. Although the early supposition that AIDS was confined to male homosexuals would be proven false, this initial assumption would persist in the public's mind well into the eighties, giving many

a false sense of security as to their chances of contracting the disease. It also led to an increased intolerance on the part of many Americans towards gay members of society.

Health statistics gathered early in 1982 showed the disease to have spread over a large geographical area. Cases had been reported in fifteen states, the District of Columbia and two foreign countries.[2] In July of 1982, the CDC shook the medical world by announcing that a second group of individuals with AIDS had been identified, hemophiliacs. It was hypothesized that hemophiliacs had contracted the disease during treatment with blood clotting factor concentrates. Although the number infected was small, the acquisition of AIDS by this group clearly suggested that AIDS could be transmitted via blood and blood products. The CDC immediately alerted the nation's blood banks that their blood supplies might be compromised and that they should no longer accept blood from individuals thought to be at risk of being HIV positive. Since many blood products produced in the United States had worldwide distribution, the further international spread of AIDS was feared. Sadly, by the end of 1983, hemophiliacs in Canada, Germany, Spain, and the United Kingdom had contracted AIDS.[3] It was not until March of 1985, when the Federal Drug Administration approved a test capable of detecting antibodies to the AIDS virus in blood, that confidence in the nations blood supply was gradually restored. While the development of such a diagnostic tool was a boon to medicine, it did pose the disturbing prospect of governmental bodies and

employers trying to force individuals to be tested.

The recognition that AIDS had spread to a third group, women, would finally drive home the point that everyone in American society was at potential risk of contracting AIDS. Many women who tested HIV positive were found to have been intravenous drug users or the sexual partners of I.V. drug users. The CDC correctly surmised that I.V. drug users were transmitting the disease to one another by the sharing of blood contaminated needles. Some of those infected had in turn passed AIDS to their sexual partners and in some cases pregnant women had transmitted AIDS to their babies. Today the majority of epidemiologists believe that AIDS is the result of one or more retroviruses which are transmitted by way of various body fluids, primarily blood and semen. While techniques for the treatment of AIDS have improved, there is as yet no vaccine against the disease. This has not however, frustrated the biomedical community whose research continues to expand at a rapid rate. The depth of commitment to controlling AIDS is reflected in the breadth and quality of medical literature devoted to it. In 1986, Dr. Helen M. Cole, then senior editor of the *Journal of the American Medical Association*, estimated that more than 10,000 medical and scientific articles on AIDS were extant with more being published at a rate of 600 per month.[4] Access to this vast lot of articles is available through such medical and scientific indices as the *General Science Index, Biological Abstracts, Index Medicus*, and several online AIDS data bases. Though these

indices librarians can give patrons access to single and multi-author papers on all aspects of the disease. To speed the availability of information, several medical journals have altered their editorial policies so that new and timely articles are readily published. Unfortunately the response and quality of articles in the popular media has not always been so credible.

POPULAR PRESS

Caution should be the byword for librarians in referring patrons to the AIDS literature of the popular press. This sizable literature often contains inaccurate, redundant, or contradictory information. One might speculate as to the part played by the popular media in regard to the public's general confusion regarding AIDS. A patron randomly selecting articles from the *Readers Guide to Periodical Literature* or from *Infotrac* has a good chance of gathering some articles with misleading or skewed information. This is not to imply that all popular articles on AIDS are inaccurate but that caution should be exercised in their selection with the more current articles being favored. While the popular press's coverage of AIDS can be questioned as to its accuracy, it does offer an informative record of media reaction to the disease and towards those suffering from it. In this sense the popular literature can offer the social scientist fruitful data for analysis. While recognizing that great difficulties can be involved in determining the varying degrees to which the media reflects public opinion or influences it, the scarcity of AIDS information

in the popular media the two years following the CDC's recognition of AIDS seems sociologically significant. The dearth of media information during this period points towards a surprising degree of apathy in the face of a serious public health threat. Other than an occasional piece on the national news or a few lines in the popular press, published AIDS information during this period appeared primarily in medical or scientific journals or in the gay newspapers of New York and San Francisco. This stands in sharp contrast to the prompt and extensive coverage the national media gave to Legionnarie's Disease and Toxic Shock Syndrome, health threats involving only a fraction of the number of people diagnosed as HIV positive. This scarcity of published AIDS information indicates a lack of interest by the American media in a disease believed confined to the gay population. Much of the media coverage during this period reflects the callous indifference of many in American society to the plight of people with AIDS. A few individuals were even reported to have suggested that the disease was a just or divine punishment for a "deviant life style". Apparently the CDC's original diagnosis of AIDS in homosexual men had contributed to a persistent and popular belief that only homosexuals or those in contact with gay men could contract the disease.

While early press accounts accurately reported the connection between AIDS and certain gay sexual practices, they also tended to reinforce society's preexisting homophobic

predilections. Popular magazines and newspapers commonly referred to AIDS as the "gay plague" or "gay cancer", setting the stage for many in our society to use the homosexual community as a scapegoat for explaining a nationwide epidemic. The *Reader's Guide to Periodical Literature* offers an excellent means for studying the publishing trends of the popular press. The first AIDS articles indexed in the *Reader's Guide* appeared in the March 1981 to February 1982 volume. Librarians may find it interesting to note that the first five indexed AIDS articles are not found under the heading of AIDS but under that of HOMOSEXUALITY. The *Reader's Guide* would begin using AIDS as a separate heading about the time that the first popular articles appeared which suggested that AIDS could be contracted by the non-gay community. The articles indexed in the 1982-83 *Reader's Guide* reflect a transition period in public awareness, besides such titles as "Being Gay is a Health Hazard" are "Homosexual Plague Strikes New Victims" and "Young Victims (Acquired Immune Deficiency Syndrome discovered in children)". As these titles suggest, many popular articles of this period implied that culpable homosexuals were somehow responsible for the spread of AIDS to "innocent victims". Implicit was the suggestion that certain individuals with AIDS (children) were deserving of sympathy while homosexuals, I.V. drug users, and prostitutes with AIDS were not. *Newsweek Magazine* in its April 13, 1983 issue reflected and no doubt helped to increase public anxiety over the disease by declaring on its cover that AIDS, "May be the public health threat of the

century". By early 1984 public concern with the disease had grown to the point that AIDS become standard fare for the media. AIDS as a topic sold magazines as it continues to today.

Unfortunately, many popular articles on AIDS have tended towards the sensational and have failed to provide pertinent and accurate information. The then Surgeon General of the United States, C. Everett Koop apparently shared this concern when in 1988 he ordered booklets containing accurate AIDS prevention information sent to every household in the United States. Librarians can likewise be in a position to direct patrons to accurate information. The more studied and even approach of the medical and social science literature should in this regard be favored.

SOCIAL AND BEHAVIORAL SCIENCE LITERATURE

As the biomedical community carried out its search for AIDS treatments and a vaccine, members of the various social and behavorial science disciplines were also actively studying AIDS. The resulting literature records the varied research of these disciplines as they tackled new areas of AIDS investigation. Here are documented the research practices of those dealing with the psychological trauma of AIDS, studies of societal reaction to the disease, and strategies for behavorial modification which if implemented might slow the disease's spread. While this literature clearly has a unique focus, its study falls within the framework of traditional social science investigation. For this reason, libraries with strong social science collections in

general and with specific strengths in the areas of Psychology, Social Work, Medical Sociology and Medical Anthropology can offer strong support to patrons undertaking psychosocial research on AIDS.

The AIDS literature of the social and behavorial sciences did not appear in published form until late in 1983 early 1984, nearly three years after the CDC's initial notification. There are several reasons for this apparent lag in publication. First of all, the number of people with AIDS was not initially large enough for the special psychological and social stress of the disease to be readily apparent. Secondly, it seemed reasonable that this new disease like others, would soon be controlled by modern medicine. After all, the outbreaks of Legionnaires Disease in 1976 and Toxic Shock Syndrome in 1979 had been successfully dealt with. It would take time for early optimism to fade and the realization to develop that the medical community could not cure AIDS. Finally, good research takes time to formulate, carry out, write up, and publish.

In 1982, Thomas J. Coates and his colleagues proposed that a multi-disciplinary approach in which behavorial and medical researchers collaborated might lead to a clearer understanding of disease than a purely medical approach, that a new "paradigm" integrating both behavorial and biomedical conceptualizations of health and disease might bear fruit.[5] In applying this type of approach to AIDS, Croates et al, wrote in a pivotal article that,

> "Psychosocial research is essential to understanding and treating AIDS and what appear to be AIDS related conditions (ARC'S). Evidence from research on other chronic and infectious diseases has demonstrated that psychosocial factors may increase susceptibility to disease, influence the course of the disease and contribute to health promoting or health damaging behaviors. A problem of this complexity requires a comprehensive approach ...[6]

As had been the case with initial medical research, early psychosocial AIDS research focused on the gay community. While these communities were easily identified, researchers were not always welcomed by them. Decades of research containing explicit or implicit homophobic or heterosexual bias had lead many gays to mistrust the objectivity of investigators. Psychologists from the University of Michigan, being sensitive to this, developed a pilot collaborative arrangement with key members of one gay community's health and political organizations. By explaining their research interests, awareness of historical bias, and offering members the opportunity to work with rather than simply be studied by researchers, they succeeded in gaining the trust essential to meaningful research.[7] Such open and objective approaches to investigation have increasingly become the norm, proving not only effective in AIDS research but in debunking many misconceptions concerning gays and the homosexual life style. Access to the knowledge obtained by psychologists and social workers in the treatment of individuals with AIDS is described in the psychological literature and can be easily identified in *Psychological Abstracts* and *Social Work Abstracts* as well as in

specialized online AIDS data bases. Librarians might consider adding the resulting publications to their collections as well as other offshoots of psychosocial AIDS research.

While our society at present has the ability through advances in medicine and mental health care to prolong the lives and ease the psychic trauma that accompanies AIDS, these advances have not been made equally available to all HIV positive individuals. For example, intravenous drug users, the fastest growing HIV Positive group have been largely ignored. Ethnic composition, poverty, language and literacy problems have all complicated getting the message across that contaminated needles and unsafe sex practices spread AIDS. Incredibly where there has been success in reaching members of this group, significant numbers have sought out treatment only to be turned away from under funded and overcrowded programs. The relative scarcity of treatment and prevention programs for I.V. drug users seems to reflect a societal willingness to overlook the problems of this burgeoning group. Such unenlightened, divided views of society clearly pose a detriment to the control of AIDS and suggest that AIDS will continue to spread. Though librarians like others in our society may feel great frustration with this, they can take some solace that through carefully developed library collections and attentive reference service, information is available for those involved in a long and difficult struggle.

ENDNOTES

1. Centers for Disease Control, "Pneumocystis Pneumonia - Los Angeles," *Morbidity and Mortality Weekly Report*. *30* (1981):250-252.

2. James Curran, "Acquired Immunodeficiency Syndrome." In *Aids From the* Beginning, ed. Helen M. Cole (American Medical Association, 1986), pxxi.

3. Ibid.

4. Helen M. Cole, ed., *Aids From the Beginning*. (Chicago: American Medical Association, 1986), p. xviii.

5. T.J. Coates, A.C. Petersen, and C.L. Perry, (eds). *Promoting Adolescent Health*. (1982) New York: Academic Press.

6. T.J. Coates, L. Temoshok, and S. Mandel, "Psychosocial Research is Essential to Understanding and Treating AIDS," *American Psychologist*. 39 (1984), p.1309.

7. Jill G. Joseph, "Coping With the Threat of AIDS: An Approach to Psychosocial Assessment," *American Psychologist*. 39 (1984), p. 1297.

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